The Connection

Fall Edition 2023

A Publication of the Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

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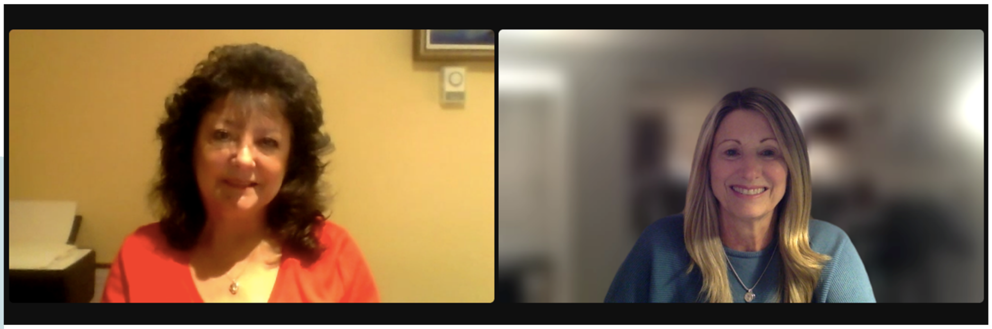
Meet our Toronto Chapter Leaders!



By Judy Haust, Vice/Past-President, ANAC

Choosing to be "roomies" in a Kitchener (ON) hotel while attending an educational and networking event hosted by ANAC cemented an already growing friendship between Kathryn Harrod and Linda Steele, who had first met at a Toronto Chapter meeting in 2010.

Since 2009, Kathryn had been assisting Lynda Nash when the first Toronto leader, Joanne Bennett, moved away from Toronto after five years in the leadership role. For quite a while, there was just a core group of five to seven individuals who kept returning to the Toronto meetings. Linda Steele was one of those regular participants.

Fast forward to 2019, when Lynda Nash "retired" as long-time chapter leader, and a well-seasoned Kathryn inherited the leadership role. When asked, Linda Steele was more than willing to step up to assist her friend, Kathryn. They complement one another as leaders and together have successfully supported ANAC members throughout the pandemic and beyond, mostly by virtue of "virtual meetings."

The transition from in-person to online meetings after the onset of the 2020 COVID pandemic was no piece of cake! Thankfully, Linda's tech

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expertise and efficiency proved invaluable. She embraced the online platform with ease, having co-led in-person meetings only briefly. For Kathryn, on the other hand, having co-led in-person meetings for more than ten years, the transition was a bigger challenge. With her sense of humour and playful manner, Kathryn still misses meeting in person. She notes that it's much easier to make sure everyone has an opportunity to contribute when the meetings are in-person, and that there's an "energy" in the room she feels is lacking with virtual meetings. In addition, several regular attendees of the Toronto Chapter meetings (when held at CHS) no longer attend, either because they are uncomfortable using computers, or they need to lip-read, something that is not really possible with so many faces appearing on the screen at once. Of course, there are pros and cons for both platforms, but that's a subject for another day!

This article will focus on the people, not the platforms: Kathryn and Linda are familiar faces to many of you, but that's not the case for all of our members across Canada. So, let's find out how they learned about ANAC, what it means to them, and why they are still faithful members and volunteers going on 18 and 14 years respectively! Furthermore, what do they do when they're not spending time volunteering with us?

> While having an acoustic neuroma has been life-changing for Kathryn and Linda, their ANs do not define them. It's simply a reality they live with that's hard to explain to anyone who has not gone through a similar experience.

Kathryn discovered ANAC only after her surgery, in 2005, when a pamphlet mysteriously appeared on the tray at her hospital bedside. Her first thought after reading through it was, "Dang, I wish I'd known about this before my surgery!" Similarly, Linda Steele discovered ANAC after her surgery in 2010, having first discovered ANA in the United States by surfing the net. (Thankfully, ANAC now has a higher profile with Mr. Google!) Linda started to attend meetings not long afterwards.

While having an acoustic neuroma has been life-changing for Kathryn and Linda, their ANs do not define them. It's simply a reality they live with that's hard to explain to anyone who has not gone through a similar experience. For both, the journey has been challenging in different ways. Each underwent *translabyrinthine* surgery and have single-sided deafness as a result. They also both suffer with dry eyes and laugh together about the many "lotions and potions" they have to carry around in their handbags. Both had relatively small tumours. In Kathryn's case, when she discovered there was something in her head that shouldn't be there (after experiencing "weird episodes" that prompted her to see an ENT), she wanted it out a.s.a.p. and didn't think twice about choosing surgery over radiation. In Linda's case, her

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small tumour was extremely symptomatic. After a stress-filled year of misdiagnoses and research, she finally admitted to herself that something needed to be done as the symptoms were getting worse. Concerned about the possibility of losing her job because she felt her difficult symptoms were compromising her performance, she also opted for surgery.

Kathryn's most significant side effect of surgery was having to deal with a droop on one side of her face for which she underwent facial rehabilitation, returning to her desk job in central Toronto three months after surgery. As it turned out, Linda returned to work much too soon, after just two months. A year later, she had to go on leave because she was still suffering from severe chronic headaches triggered by the surgery, among other issues. For seven years, Linda enjoyed a less demanding job working in hospitality on private yachts, cruising up and down the US east coast and throughout the Caribbean. Today, she is back at the CBC as one of only two people who license CBC content from 1940 to the present. They receive thousands of licence requests worldwide for use in documentaries, publications, etc. Even now, Linda continues to experience headaches, but fewer than before.

Kathryn recently retired and moved out of Toronto to a small community northeast of the city. While missing the daily camaraderie of office life (as well as the annual Christmas parties!), Kathryn now has more time for her many hobbies. These include painting landscapes (ed. note: very impressive ones, in fact!) using oils and acrylics, photography, Zumba, and kayaking in the summertime. For years, Kathryn was a volunteer photographer for the Mississauga-based SNAPD, a local event newspaper that, sadly, folded as a result of the pandemic, when *no* events were taking place, virtually or otherwise. Prior to that, she had managed to arrange for the Toronto SNAPD to do an article on ANAC. Married for 36 years with a grown daughter, Kathryn is sorely missing her cat, Cleo, who "went to heaven last year on Boxing Day". She looks forward to being able to pamper a new fur-baby.

Linda shares two passions with Kathryn: photography and animals. She favours night photography (such as highways with cars) and skylines, and some of her photographs have been published. One year, Linda had the privilege of photographing the Northern Lights while in Iceland . . . speaking of which, she also loves to travel! Her former job involved making numerous trips to Europe and then, of course, there were the seven years spent yachting, and regular visits to family in the United States. Her passion for animals led her to volunteer as a Customs Coordinator with a dog and cat rescue organization, a position she's

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held since 2016. She has two cats of her own, Bailey and Emmett.

There's a familiar saying: *When life deals you a lemon, make lemonade!* Kathryn and Linda were each diagnosed with an acoustic neuroma, but they've since been making lemonade *tirelessly* by sharing their stories and listening to the stories of others who are going down the same road. As Linda pointed out, she can take part in various volunteer activities, but volunteering with ANAC is different because only those who have an acoustic neuroma can truly understand what the others may be going through. And as Kathryn put it, she greatly appreciated all the support of family and friends while going through such a traumatic experience, but having the support of her ANAC family is "a different ballgame, a totally different realm".

ANAC is so grateful to these two long-time volunteers and so happy about the friendship that's developed between them, thanks to having met at a support group meeting. How true that *behind every cloud, there's a silver lining!*

Welcome, Samantha!

ANAC is so pleased to welcome Samantha Song as our newly-appointed Secretary, as of November 2023. Samantha successfully graduated from her *Bridge to Employment in Media and Communications* (BEMC) program in September, having completed a two-month volunteer placement with ANAC. Bringing a wealth of knowledge and experience from her home country, China, we are so grateful for the time, energy and passion she has devoted to ANAC. Samantha delivered written communications for our new *Customer Relationship Management* (CRM) system, email campaigns, and social media—providing important content for the successful launch of our new *Members Portal* and 4th *Annual Virtual Walk* fundraising campaign. She exudes keenness, professionalism, and attention to detail, which is complemented by her thoughtfulness, positive attitude, and caring nature. We are so delighted to have Samantha join our team!

Honouring Carole Humphries

In honour of Carole Humphries' dedicated service to ANAC as Executive Director (now known as National Operations Director), ANAC's Board of Directors wholeheartedly wishes to bestow on her an Honorary Lifetime Membership. By definition, this membership lasts the individual's lifetime, and entitles the holder to attend—and exercise one vote

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Honouring Carole Humphries

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at—all Meetings of Members. Carole easily fulfills the criteria for this very special designation by having interests of ANAC over her seven-years as a consultant to the board. Scores of individuals will remember her as a soothing voice of calm and patient reassurance when they reached her on the phone, or in person, to discuss their concerns. We wish Carole all the best as she, herself, continues to return to good health after some significant medical challenges over the past year-and-a-half.

Thank you, Carole, and congratulations on your Honorary Membership!

Holiday greetings from your Board of Directors—a *year in review*

As we approach the end of 2023, we would like to congratulate our entire ANAC community on reaching this significant milestone—four decades of our association's existence! It is truly inspiring to reflect on the unwavering commitment, growth, and transformative journey our organization has experienced. Here's a closer look at the noteworthy accomplishments from the past year:

Welcomed New Leadership: The addition of Michelle Gillespie in January as our National Operations Director signifies a positive step forward in leadership, bringing new skills and fresh ideas to the table, and working from a solid foundation laid by former Director, Carole Humphries over the previous seven years.

Renewed our Strategic Plan: The identification of five key pillars—*infrastructure, connection, inclusion, growth,* and *education*—provides a clear framework that will guide our association's programs and services in the coming years.

Expanded Volunteer Base: Acknowledging the introduction of new support group leaders—Annamaria Palffy, Faye Goranson, Robynne Smith, Michel Patenaude, and Caroline Crevier—as well as the valuable contributions from ANAC members Samantha

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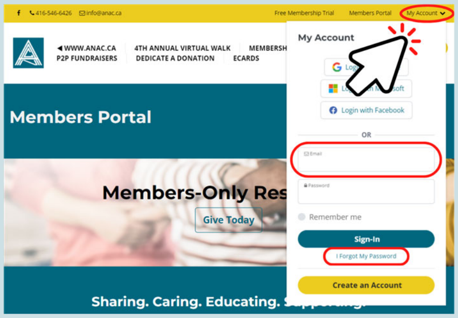
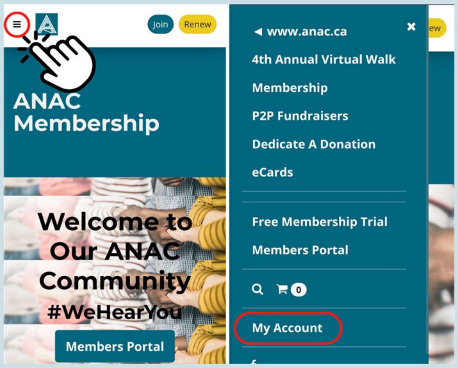
Members Portal Login

Go to **www.anac.ca > MEMBERS** (main menu)

On your computer:



On your mobile phone:



First-time login?

⇒ Click **'My Account'**

⇒ Click **"I Forgot My Password"** hyperlink

⇒ Enter your email address

⇒ Click "**Send Me a Login Link"** button and follow the email prompts to set your password

Once signed in, ***your name*** will appear in place of **'My Account'.**

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Holiday greetings from your Board of Directors—
a year in review

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Song and Mary Gould—demonstrates a commitment to a diverse and engaged team. Samantha has been supporting our communications strategy, delivering written content for our new *Members Portal*, email communications and Facebook page. Mary worked tirelessly developing a newsletter publication database which now serves as a valuable source of information to help respond to inquiries, identify information gaps, and guide new content.

Members Portal Launch: The adoption of a *Customer Relationship Management* (CRM) system showcases a commitment to improving operational efficiency and accessibility of our services. Our new *Members Portal* offers members easy and secure access to exclusive content, enhancing the overall experience and benefit of membership *(see login instructions on page 5 sidebar).*

Members Portal Login

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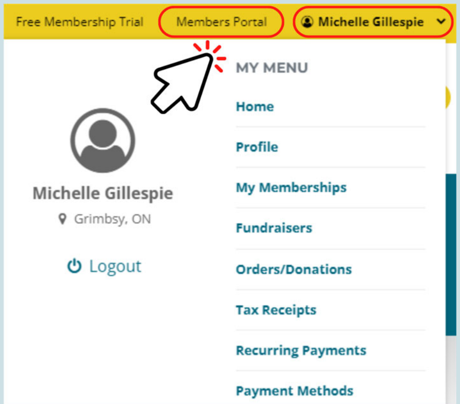
Access our secure **Members Portal** and manage your membership from **'MY MENU'.**



Expansion of Virtual Support Groups: The introduction of a new Saskatchewan/Manitoba Virtual Support Group and the recent launch of our first Quebec Virtual Support Group for French-speaking members demonstrates a commitment to inclusivity and accessibility.

Successful 4th Annual Virtual Walk Fundraiser: Raising a grand total of **$18,344** during the *4th Annual Virtual Walk* is a testament to the generosity and support of our community. This funding will undoubtedly contribute significantly to the realization of our mission and goals. We are so grateful to all those who participated, donated and/or simply spread the word!

40th Anniversary Newsletter and Celebration: Our special anniversary edition newsletter, along with our virtual *Opening Ceremony* event, presented as a kick-off to our *4th Annual Virtual Walk* and celebration of this momentous occasion, tells a remarkable story! They showcase a 40-year journey, recognize the individuals who have played pivotal roles in the association's history, as well as acknowledge the collective efforts of our many volunteers—too many to be named! Rebecca Raghubeer, President, delivers a message of deep pride, heartfelt gratitude, and a commitment to continue advocating for better care and research. Our guest speakers provide a personal touch to the celebration. A spotlight on the esteemed Virginia Garossino, a co-founding member, reflects deep connection to the

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40th Anniversary Celebration is available on ANAC's YouTube channel!

https://youtu.be/WjECfNE8KUI

Holiday greetings from your Board of Directors—*a year in review*

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association's roots and the individuals who laid the foundation for its existence. Evalyn Hrbyko, BC Support Group Leader and longstanding member, represents the boundless dedication and leadership within the association. Peggy Bray, past-president and longstanding member, brings a wealth of experience and inspiration to the celebration. Incorporating an awareness component during the ceremony emphasizes the association's commitment to educating the public about acoustic neuroma and ANAC's very existence! *If you would like to watch the video recording, access instructions are detailed on page 6 sidebar.*

As we reflect on these accomplishments, we take immense pride in the positive impact our association has had on the community over the past four decades. Here's to continued growth, success, and making an even bigger impact in the years to come!

Looking Ahead

As we kick off 2024 with a strategic plan review, we emphasize ***engagement*** and ***community-building*** as integral to the achievement of our long-term goals—particularly through resource mobilization. We are always seeking engaged community members to contribute their time, skills and resources through advocacy efforts, volunteering and/or fundraising. In the coming months, we will be sending out invitations for community members to get involved as we work on forming the following working committees and sub-committees:

Revenue Generation

- Fundraising
- Sponsorships
- Grants

Information & Resource Dissemination

- Website Content
- e-booklets
- Promotional Materials
- Webinars
- Newsletters

Peer Support Network Expansion

- In-Person Support Groups
- Virtual Support Groups
- One-on-One Peer Support

Communications

- Email Campaigns
- Social Media
- Letter-mail
- Telephone

Partnerships

Medical Advisory Committee Liaison

Volunteering can be a great way to find a deeper sense of fulfillment, purpose, and belonging, as well as an opportunity for both personal growth and professional development. Please keep an eye out for volunteer postings in 2024 and get ready to make a collective impact. **We are a TEAM—Together. Everyone. Achieves. More!**

As we close out 2023, may this great sense of gratitude, pride and accomplishment carry our organization into the next 40 years! We would like to wish everyone a safe, joyful, and healthy holiday season. May the upcoming year, 2024, bring even more success and growth for our association as we continue to stand as a beacon of hope for those affected by an acoustic neuroma. Thank you for your support, and all the best to each and every one of you!

Holiday wishes and warm regards,

Your ANAC Board of Directors

The importance of self-advocacy in the rare disease community—*ANAC offers guidance and tips on how you can make a difference for yourself and others*

By Michelle Gillespie, National Operations Director, ANAC

The *National Organization for Rare Disorders* (NORD) estimates that acoustic neuromas affect about 1 in 100,000 people in the general population, however, the actual incidence may be higher than reported as it is believed many remain undiagnosed or misdiagnosed. Whether or not you self-identify as having a rare disease or disorder, it is because of the rarity of acoustic neuroma that many of us have faced obstacles along the journey to diagnosis, treatment and symptom management.

The *Experiences of Rare Disease Patients* study conducted by *Canadian Organization for Rare Disorders* (CORD) (full report released February, 2023) found a common need among those surveyed to self-advocate, requiring them to research their disease and seek out treatment on their own. Further, participants felt the need to advocate for other support services, such as mental health care. The study found a gap in patient support information and counselling, with only about 40% of respondents given information about patient organizations or support groups at the time of diagnosis. You may find that these study findings align with your own personal experience navigating your acoustic neuroma diagnosis within our healthcare system.

Self-advocacy empowers you to take an active role in your healthcare journey. It requires you to seek information, ask questions, and collaborate with your healthcare team for a personalized approach to treatment—ensuring the best possible care and outcomes given your unique circumstances and individual needs. Additionally, by becoming more active in your ANAC community, you can contribute to raising awareness and improving the overall understanding of acoustic neuromas, leading to earlier diagnosis and better outcomes and quality-of-life.

Listed below are some common challenges expressed by our members, along with some guidance and self-advocacy tips we hope you will find helpful. We understand that advocating for yourself can be overwhelming, exhausting, and uncomfortable, especially during an already stressful time. However, it can make a huge difference for both you and your ANAC community, as well as ensure you take advantage of the many benefits of your ANAC membership!

Lack of Awareness

Often the presenting symptoms of an acoustic neuroma are subtle, overlooked, or attributed to other more common health conditions. Lack of awareness among the general public and even among healthcare professionals contributes to delayed or misdiagnosis. We know that early detection can significantly improve the outcomes and quality-of-life for individuals diagnosed with an acoustic neuroma. *So, what can you do?*

Get involved in ANAC's awareness campaigns: Being active on

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The importance of self-advocacy in the rare disease community…

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our social media channels is a simple and effective way you can help spread the word about our mission. Help us use the power of social media to reach a wider audience! Connect with us on Facebook **@AcousticNeuromaCanada**—like, share and comment on our posts. Collectively, these simple actions can make a huge difference.

Tell your story and share your experiences: This not only provides emotional support to others and fosters community connection, but it also contributes to a collective body of knowledge about acoustic neuromas which can play a role in raising awareness, educating both the general public and the medical community, enriching patient-practitioner relationships, and encouraging research.

Limited Information and Research

Rare conditions such as acoustic neuroma, which affects a limited patient population, generally receive less research funding compared to more common diseases. This results in a lack of available information about the condition, leaving many struggling with uncertainty around optimal treatment options and long-term outcomes. *So, what can you do?*

Explore our online resources: Find a wealth of information and resources on our website at www.anac.ca > **LEARN**

Read our newsletter, *The Connection:* Our own publication contains informative articles from medical professionals as well as personal stories from ANAC members—a valuable source of information and insights into the diagnosis, treatment and management of acoustic neuroma.

Log in to our NEW Members Portal *(see login instructions on page 5 sidebar)***:** Access additional members-only resources such as past digital newsletters and webinar recordings.

Participate in fundraising campaigns: As a non-profit, our long-term sustainability depends on the generosity of our members and donors. Your support enables us to make a tangible impact and further our mission. Fundraising is also an opportunity to build community, expand our support networks, and raise awareness about our cause.

Volunteer your time and skills: Dive deeper into our mission by responding to upcoming opportunities to serve on working committees. From event planning to establishing partnerships with aligned organizations, your advocacy efforts will strengthen our voice, promoting research and advancements in the field of acoustic neuroma (see *Holiday greetings from your Board of Directors…* for more information).

Delayed or Difficulty Finding Treatment

Understanding and navigating the healthcare system can be complex, and finding healthcare providers with expertise in acoustic neuroma

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The importance of self-advocacy in the rare disease community…

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can be challenging. Patients may need to travel long distances to consult with specialists, which can be logistically and financially burdensome. Those diagnosed with an acoustic neuroma may need to take their own initiative to seek out qualified specialists and find the most accurate, up-to-date information about their condition. *So, what can you do?*

Consult our Centres of Excellence directory: Visit www.anac.ca/medical-directory-registry to find a specialist qualified to treat acoustic neuroma.

Consult our Canadian Facial Therapists directory: Visit www.anac.ca/specialized-facial-therapists to find a specialist qualified to treat facial paralysis.

Connect with our Medical Advisory Committee: Obtain expert support by submitting a non-urgent medical inquiry or an application for a ***Multi-disciplinary Assessment.*** Log in to our *Members Portal* to review the submission requirements.

Be well-informed: There is a wealth of information on our website where you can learn about acoustic neuroma, its symptoms, and the treatment options available to you. Be proactive in researching and discussing potential treatment options with your healthcare team. Know your options and exercise your right for a second opinion when in doubt. Take control over your own health and well-being. Learn about strategies to communicate effectively with healthcare professionals and valuable questions to ask. If you're unable to advocate for yourself because of poor mental state or otherwise, ask a friend or family member to be your advocate and attend your medical appointments with you.

Access our support services: Join a support group, or request one-on-one support, and connect with like-minded individuals to learn about their personal experiences and gain valuable insights. These services are easily accessed through our *Members Portal.*

Psychosocial Impact

The diagnosis, treatment and management of both acute and chronic symptoms of acoustic neuroma can have a profound impact on mental health. The uncertainty, lack of information, and challenges in accessing appropriate care can contribute to stress and anxiety. Some individuals describe traumatic experiences around diagnosis and treatment. Symptoms and outcomes of treatment can be life-altering, leaving individuals experiencing feelings of grief and loss. The rarity of the condition may also contribute to a sense of isolation for those diagnosed. *So, what can you do?*

Recognize the importance of mental health: Communicate

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The importance of self-advocacy in the rare disease community…

(cont'd from page 10)

openly with your healthcare team about the psychosocial aspects of your diagnosis and seek appropriate support.

Join an ANAC support group: Connecting with others who can truly empathize can be crucial for emotional support and a valuable source of information—providing hope, comfort and a sense of relief from feelings of isolation, fear and anxiety.

Take control of your own health journey, get the most out of your ANAC membership, and help make a positive impact on your ANAC community! Together, we can overcome the challenges of acoustic neuroma in pursuit of a better quality-of-life for those affected by this rare brain tumour.

Lemonade Stand

Our earliest *The Connection* newsletters featured a column called *Readers Share Hints* which, in 1993, was renamed *The Lemonade Stand*—continuing as a collection of practical suggestions, clever adaptations and stories of life adjustments, fostering the saying "When life serves lemons, make lemonade." We are bringing this popular column back! If you have any words of advice to share with your ANAC community, please email **director@anac.ca**. Thanks!

Is your AN causing you excessive mucous production? Problem solved!

Peggy Bray, past-president and longtime member of ANAC, is grateful to have found a solution to her hypersecretion (i.e., excessive mucous production) from her right nostril on her acoustic neuroma (AN) side, a long-term problem which became exacerbated whenever she got the slightest bit overheated. Many thanks to Susan Rankin, BScPT, MHSc, physiotherapist specializing in *Facial Neuromuscular Retraining,* for posting the inquiry to her network of international professionals, an example of knowledge sharing through the power of the internet! We acknowledge the expertise of Jodi Janczewski from the University of Wisconsin who shared information about the cause and the possibility of surgical treatment, as well as Helen Martin in the United Kingdom who suggested a particular nasal spray, *Ipravent*, as a possible remedy.

Through this collective knowledge, it was discovered that Peggy is most likely experiencing the above described issue as a result of a phenomenon that is described in the following excerpt from the research paper, *Pseudo-Cerebrospinal Fluid Rhinorrhea Resulting from Aberrant Cross-Innervation of Trigeminal and Facial Nerves following Skull Base Surgery*, published in the *Journal of Neurological Research Reports*

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Is your acoustic neuroma causing you excessive mucous production? Problem solved!

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(Benjamin L. Grannan, MD, Wenya Linda Bi, MD, PhD, and Ian F. Dunn, MD, January 2015).

> "This phenomenon was first described by Cusimano and Sekhar, who noted clear fluid hypersecretion without evidence of a dural CSF leak following skull base procedures involving exposure of the petrous or cavernous internal carotid artery and transection of the greater superficial petrosal nerve. They hypothesized that the effect was due to injury to the periarterial sympathetic and parasympathetic fibers traveling to the nasal mucosa followed by aberrant reinnervation leading to a relative parasympathetic state. They also noted that the nasal hypersecretion tended to be exacerbated by physical activity, elevated ambient or body temperature, and intense emotional experience."

Here is a link to the full article: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4520968/

After considering surgical options to treat this condition, Peggy was delighted to try the recommended nasal spray and has found much relief! After using the nasal spray for some time, she reports:

No surgery required, just daily + regular use of the nasal spray, *Ipravent* (Ipratropium Bromide: Topical Anticholingeric, 0.06%) in Canada. Be sure to aim the spray nozzle away from the bony cartilage in the centre of your nose. The medication causes this sensitive area to swell. It's also very drying. At night I swab my nostril with moisturizing gel, and swabbing the inside of the nostril with Vaseline has also been suggested. I also spray my nostril with a moisturizing preparation in the morning and at night. I use half the recommended dosage, meaning one spray morning and evening. It's effective for me when used in this way. *Ipravent* requires a prescription.

Thank you, Peggy, for sharing this solution! We hope others in our ANAC community will also benefit from this information.

"If all that we see are the scattered pieces of 'what was,' the story of 'what is yet to be' will never be told. If, however, we are able to envision the pieces as what they are now freed to be, the story of 'what is yet to be' will stand among the greatest ever told."

~ Craig D. Lounsbrough

20 years and going strong

By Louise Rachlis, ANAC Member

It's hard to believe, but it has now been 20 years since I received a diagnosis of "acoustic neuroma", followed by Gamma Knife radiosurgery.

I shared my "Silver Lining" story in the ANAC newsletter in 2007, nearly two years after undergoing Gamma Knife.

I'm delighted to tell everyone that I have been fine since. I still receive yearly MRIs—which have shown the tumour hasn't grown—and no other treatment has been needed.

First, a quick summary of my diagnosis and treatment:

The treatment was the culmination of a process that had begun in fall 2003, when I finally told my family doctor that I seemed to be having trouble hearing. She referred me to an ear, nose and throat (ENT) specialist, which led to a CAT scan and an MRI. That led to a referral to a neurosurgeon. Months evolved in between all those appointments, and each one led to several phone calls to arrange an appointment for the next.

Finally, the diagnosis was "acoustic neuroma." It was a relief to have my problem given a name, and that name wasn't as bad as I'd feared. I learned that with MRIs more readily available, acoustic neuromas were being diagnosed more easily, but that their incidence was still very rare.

Since my acoustic neuroma was slow-growing, about one centimetre, I had three initial choices—do nothing and observe, an operation through the ear to remove it, or radiosurgery. I was monitored by MRIs for several years as my hearing continued to deteriorate.

By June 2006, the neuroma had grown to two centimetres, and it was time to see the neurosurgeon again and be confronted with the same choices of surgery or different kinds of radiation. I opted for radiation, grateful to have an option to surgery, and chose to have the Gamma Knife radiosurgery at Toronto Western.

Not exactly a knife, Gamma Knife uses very precise beams of radiation to treat affected areas of the brain and destroy the acoustic neuroma tumour.

Undergoing the process, I looked like something from outer space with the stereotactic head frame attached to my head with four pins. The frame stayed on my head for the entire procedure to keep me in a stable position during imaging and treatment.

I returned to Ottawa on the train the next day and was back at work two days later. I've had no problems since. While my hearing hasn't improved, I do now have a hearing aid that helps with one-sided hearing loss: The new technology is the Phonak CROS, which consists of a transmitter microphone for the ear that cannot benefit from a

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20 years and going strong

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hearing aid, and a receiver hearing aid on the better hearing ear. When sound comes from the poorer hearing side, it is wirelessly sent to the better ear. When I was getting my fitting, the audiologist told me that another of his clients was so happy with the new technology that he hugged him and sent flowers. They are now part of my life, but so small that no one notices unless I point them out.

At age 76, I continue to write, exercise, enjoy my family, and do whatever I want. The tumour has not grown any further.

It is heartening that 20 years on there is much more understanding and earlier diagnosis. I'm happy to help raise public awareness of acoustic neuroma and to support those in the ANAC community.

Ready to share your story?

Sharing your acoustic neuroma journey with our ANAC community can help reduce feelings of isolation and provide hope, comfort, empathy and understanding to others facing similar challenges.

Collectively, stories are also powerful tools for raising awareness, as well as educating the public and medical community about acoustic neuromas, improving patient-centered care and encouraging research into better quality-of-life treatments.

Please email **director@anac.ca** if you would like to share your journey with us!

Are you getting the most out of your ANAC membership?

Virtual Support Groups

One-on-One Peer Support

Newsletter, *The Connection*

Webinars

Expert Support

DID YOU KNOW?

Your $45 annual membership fee is eligible for a $40 charitable giving tax receipt!

Support Group Contacts and Upcoming Meetings

All members welcome!

You can now register for *any* upcoming meeting through our new **Members Portal** by visiting www.anac.ca > **MEMBERS** *(www.anac-givecloud.ca/support-groups)*.

Meetings are held *virtually* via Zoom.

Members automatically receive emails from their local chapter.

Please call 416-546-6426 or email director@anac.ca to receive email invitations and reminders for any group outside your region.

BRITISH COLUMBIA (PROVINCIAL)

Next meeting TBD

Evalyn Hrybko
evalynhrybko@gmail.com
250-282-3269

Caroline Bradfield
CarolineANgroup@shaw.ca
250-897-3553

Gavin Donatelli
gavindonatelli@hotmail.com
250-891-6487

ALBERTA (PROVINCIAL)

Mary Jane Hradowy
maaavelous@me.com
587-216-4448

Seeking a co-leader!
Contact director@anac.ca

SASKATCHEWAN/ MANITOBA (PROVINCIAL)

January 24, 2024 @ 6:30 p.m. CST (Central Standard Time— Regina/Winnipeg)

Robynne Smith (SK)
robynne@sasktel.net
306-260-6098

Annamaria Palffy (MB)
palffya@hotmail.com
204-952-4409

Faye Goranson (MB)
fayegoranson@gmail.com
204-762-5611

KITCHENER-WATERLOO, ONTARIO (REGIONAL)

Wednesday, February 21, 2024 @ 7 p.m. EST (Eastern Standard Time—Toronto)

Linda Darkes
pldarkes47@yahoo.com
516-696-3445

Helen Horlings
healto@rogers.com
519-954-5581

TORONTO, ONTARIO (REGIONAL)

Tuesday, January 30, 2024 @ 6:30 p.m. EST (Eastern Standard Time—Toronto)

Kathryn Harrod
kath.harrod@live.ca
416-454-9005

Linda Steele
lindasteele2@gmail.com
416-993-0065

OTTAWA, ONTARIO (REGIONAL)

Seeking Volunteers!
Contact director@anac.ca

NEW! QUEBEC (PROVINCIAL) FRENCH-SPEAKING

Next meeting TBD

Michel Patenaude
michelpatenaude30@gmail.com
514-714-9868

Caroline Crevier
carolinecrevier11@hotmail.com
514-809-8357

ATLANTIC CANADA (PROVINCIAL)

Seeking Volunteers!
Contact director@anac.ca

About Us

The *Acoustic Neuroma Association of Canada* (ANAC) is a registered, peer-led charity—the only one of its kind in Canada dedicated to serving individuals impacted by an acoustic neuroma.

All of the services and resources offered through membership would not be possible without the support and generosity of our members and donors.

thank you

OUR VISION

A world that understands acoustic neuromas.

OUR MISSION

To provide accurate, up-to-date information and ongoing support to individuals with an acoustic neuroma and to their families to help improve their quality of life.

Donate Today!

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Connect with ANAC!

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7 B Pleasant Blvd.
Toronto, ON M4T 1K2

1-800-561-2622
1-416-546-6426

director@anac.ca

www.anac.ca

@AcousticNeuromaCanada

Our Leadership Team

Rebecca Raghubeer, President

Judy Haust, VP/Past President

Adam Rochacewich, Treasurer

Anna Gurdon, Director

Nicholas Kucharew, Director

Matt Madott, Director

Samantha Song, Secretary

Michelle Gillespie, National Operations Director (Consultant)